

Progress on the Implementation of IC 16-38-4-7 (Birth Defects & Problems Registry) as amended in First Regular Session 112th General Assembly (2001)
Reporting Period: July 2011 – June 2012

The Indiana Birth Defects and Problems Registry (IBDPR) is a population-based surveillance system that seeks to promote fetal, infant, and child health. The purpose of the Registry is to prevent birth defects and childhood developmental disabilities and to enhance the quality of life of affected Indiana residents.

Birth defects are conditions present at birth that affect the structure or function of an infant's body. They can cause physical, mental, or medical problems. Birth defects affect about 1 in 33 babies born in Indiana each year. They are the leading cause of infant deaths, accounting for more than 20 percent of all infant deaths (*National Vital Statistic Report*, vol. 60, number 4, 2010). Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects. Annual costs for birth defect-related conditions are nearly \$2.5 billion (*Morbidity and Mortality Weekly Report*, January 19, 2007). Some of these causes are entirely preventable, while others could be identified early and treated or managed in order to improve the quality of life of affected infants and their families.

The 1986 Indiana General Assembly enacted a law (IC 16-4-10-6) to establish the Birth Defects & Problems Registry by January 1, 1987. In 2001, the Indiana Birth Defects & Problems Registry law (IC 16-38-4-7; 410 IAC 21-3) was amended to allow additional data sources to be used to improve the quality of the data. Data from the Indiana Birth Defects & Problems Registry is used to detect trends in birth defects and suggest areas for further study; to identify epidemiological factors associated with birth defects; to address community concerns about the environmental effects on birth outcomes; to evaluate education, screening, and prevention programs; and to establish efficient referral systems that provide special services for the children with identified birth defects and their families.

Case Ascertainment

The Indiana Birth Defects and Problems Registry (IBDPR) is considered a “passive” system because initial case ascertainment is through the electronic submission of hospital discharge data with defined ICD-9-CM codes that identify birth defects and problems. However, in the early stages of program development, it was determined that up to 25% of the hospital discharge data was invalid. Therefore, program protocols were updated to include chart audits (indicative of an “active” birth defects registry) on 46 CDC-targeted conditions; these chart audits are utilized to ensure that the data submitted to the CDC & the Indiana legislature is as accurate and valid as possible and to ensure that appropriate information is sent to families of children reported with at least one birth defect.

Hospital Reporting:

Hospitals are required to report birth defects data to the IBDPR when coding of hospital discharge records is completed each month. Currently, all 111 reporting facilities submit monthly discharge data through the ISDH State Health Gateway web portal. As of August 2012, 58 facilities had completed reporting up to July 2012; 29 facilities had reported up to June 2011; 12 facilities up to May 2012; seven (7) facilities up to April 2012; and two (2) facilities up to March of 2012. The remaining three (3) facilities have reported up to December 2011. Several reasons exist for delays or irregularities in data reporting, such as changes in data collection or recording systems and lack of resources (including a lack of health information management/medical records or information technology staff).

Physician Reporting:

The IBDPR uses physician reporting to identify children with birth defects who may not be diagnosed at birth and may, therefore, be diagnosed in a doctor's office rather than in a birthing facility. Since IBDPR staff considers a physician's submission to be confirmation of a diagnosis, no chart auditing is done on charts in a physician's office. If the IBDPR receives duplicate information from a birthing facility and no chart audit has been completed, the physician's report will serve as confirmation of that birth defect and no chart audit will be done at the hospital. IBDPR staff expect that reports of children with autism and fetal alcohol spectrum disorder will be ascertained primarily through physician reporting, since the diagnostic criteria for both conditions include developmental delays that are not detectable at birth.

In December 2011, an electronic information packet was sent to physicians in recognition of January being Birth Defects Awareness Month and to encourage the use of the web-based Physician Reporting Center within the ISDH State Health Gateway. The electronic packet included a letter from the State Health Commissioner, reminding physicians of the legal requirement for reporting to the IBDPR and including links to the ISDH State Health Gateway, a list of reportable conditions, and instructions for accessing and creating an account within the ISDH State Health Gateway. This information packet was e-mailed to 3,588 Indiana health care providers from the ISDH State Health Commissioner's e-mail account. Provider e-mail addresses were obtained by combining information from the Indiana Professional Licensing Agency and the Centers for Medicare and Medicaid Services.

In another effort to promote the web-based Physician Reporting Center and increase the number of physicians reporting to the IBDPR, IBDPR staff collaborated with the Indiana State Medical Association (ISMA), the Indiana Chapter of the American Academy of Family Physicians, and the Indiana Chapter of the American Academy of Pediatrics to publish an article about the web-based Physician Reporting Center in each of the agencies' newsletters in July 2012. This article contained a brief introduction of the IBDPR, a reminder about the legal requirement for physicians to report to the IBDPR, and instructions for accessing and registering with the ISDH State Health Gateway.

During the current reporting period (July 2011 – June 2012), a total of 561 reports, representing 546 individual children with birth defects, were submitted by 19 physicians and 8 psychologists. There were no reports from other authorized health care providers (such as osteopathic physicians and medical residents) during this period.

Application Development

During this period, a new web application was developed by ISDH Genomics & Newborn Screening Program staff in an effort to improve the quality of the integrated data (including data from Vital Records and newborn screening) utilized by staff.

Program Development

As stated earlier, data from the Indiana Birth Defects & Problems Registry (IBDPR) is used to improve the quality of data available on birth defects in Indiana and to provide information (including educational information and a list of available resources) to the parents/guardians and primary care providers of children with confirmed birth defects.

Each time a change occurs within the rules regarding case ascertainment, IBDPR staff ensures that all appropriate personnel, including health care providers and birthing facility staff, receive timely notification of the legislative change.

Due to the need to update components of the IBDPR (including components that load and process hospital discharge data), IBDPR staff postponed the implementation of mailing information packets (including educational information and resources) to primary care providers and parents/guardians of children with at least one confirmed birth defect. Families who receive this packet from the IBDPR will receive double-sided pages with English on one side and Spanish on the other. The effectiveness of these mailings will be evaluated once this component of the program is fully functioning.

National Meetings Attended

In February 2012, one staff member attended the 14th annual meeting of the National Birth Defects Prevention Network (NBDPN) in Washington, DC (titled *Advances and Opportunities for Birth Defects Surveillance, Research, and Prevention*). Attendance at the conference was funded by the Centers for Disease Control and Prevention (CDC). This workshop was designed to enhance relationships between federal, state, and professional organizations that are working towards common goals, as well as to provide an opportunity for participants to collaborate on new initiatives and discuss successful efforts related to reducing and preventing birth defects.

Statute Requisites

Since the IBDPR collects data on children up to five years of age on a daily basis, compiling reports (covering the same time period) on different dates may result in different values. Data for this report was compiled on 09/07/2012. Data within these

reports is grouped into a range of 5 total years, as specified by the CDC for its national publication. This report includes Indiana data for children who were born in 2005, 2006, 2007, 2008, or 2009. According to Vital Records data, from 2005 – 2009, a total of 436,731 live births occurred to mothers who were Indiana residents.

The data presented in Tables 1 – 3 were obtained from the data extracted from hospital discharge (UB-92) records and submitted to the IBDPR by statewide hospitals as required by the Birth Problems Registry law (IC 16-38-4-7; 410 IAC 21-3).

To verify the accuracy of hospital discharge data, the IBDPR targets 47 specific birth defects for chart auditing by IBDPR staff. These defects are recommended by the National Birth Defects Prevention Network (NBDPN); data on these targeted conditions is published annually in the NBDPN publication, *Birth Defects Research Part A: Clinical and Molecular Teratology*. Based on the information reported to the IBDPR by the state birthing facilities, IBDPR chart auditors review the medical records of children who were reported to the IBDPR to collect detailed medical information (such as surgical records and echocardiograms); this information is then reviewed by the Genomics and Cystic Fibrosis Programs Director, who determines whether each child's reported condition(s) can be confirmed, marked as "probable," or invalidated (Table 5). A "probable" condition is one that has been audited by IBDPR staff where the information obtained in the chart audit was adequate enough to determine the condition to be likely, but not adequate enough to confidently confirm the condition.

For 2005 – 2009 births, approximately 50% of the birth defects reported through hospital discharge data were confirmed based on chart audits. Of the targeted birth defects reported and confirmed, approximately 78% occurred in non-Hispanic white children, 10% in non-Hispanic black children, 8% in Hispanic children, 2% in Asian and Pacific Islander children, and 2% each for children of American Indian descent and other races/ethnicities.

The following paragraphs explain the attached tables in more detail:

Table 1 shows the number of unduplicated children reported by birthing facilities through ICD-9-CM codes at discharge for each reportable condition category. Since many children with birth defects or problems have more than one defect, some children may be included in multiple condition categories. These numbers do not reflect confirmation of the defect, merely hospital reporting.

Table 2 shows the number of unduplicated children who were reported with one reportable condition; **Table 3** shows the number of unduplicated children reported with more than one reportable condition. These tables are subsets of Table 1 and, again, do not reflect whether there is a confirmed diagnosis that supports the discharge code.

Tables 4A and **4B** reflect the sources of case ascertainment for targeted and non-targeted, reportable conditions. According to these tables, physician reporting was the sole source of information for 14% of the occurrences of autism, 38% of reports of fetal alcohol

syndrome (FAS), and 31% of reports of autism spectrum and other pervasive developmental disorders, illustrating the necessity of direct physician reporting for accurate reporting of the prevalence of these conditions.

Table 5 outlines the targeted condition categories reported by hospital discharge data where the condition was determined to be confirmed or probable based on information obtained during a chart audit. The final column, “Confirmed/Probable Percentage,” reflects the validity of the hospital discharge data reported by the hospitals by calculating how many of the reported conditions were determined to be confirmed or probable after a chart audit was performed. As stated earlier, for 2005 – 2009, approximately 50% of all targeted conditions were determined to be probable or confirmed based on information obtained during chart audits. Of note, less than 40% of all reported cardiovascular anomalies were confirmed, indicating the necessity to conduct hospital chart audits in order to validate reported data. The ICD-9-CM codes listed on the hospital discharge data often represent conditions that may possibly be present, but require additional testing or information to accurately confirm or rule out.

Table 6 includes the counts and rates (listed by race; rates calculated per 10,000 births) of confirmed and probable targeted conditions for children born to Indiana mothers during 2005 – 2009. The overall prevalence of birth defects in Indiana as calculated by this report was 285 per 10,000 births, which is aligned with national estimates.

Table 7 indicates the counts and rates (listed by race; rates calculated per 10,000 births), sorted by maternal age at delivery (less than 35 years of age at delivery or 35 years of age and above at delivery), of confirmed and probable cases of children with one of the three trisomy conditions (trisomy 13, trisomy 18, and trisomy 21) who were born to Indiana mothers during 2005 – 2009. Children with trisomy conditions have three, rather than the expected two, copies of a chromosome—for example, children born with a third copy of chromosome 21 have Down syndrome, also called trisomy 21.

Table 8 shows the counts and rates (rates calculated per 10,000 births) of confirmed and probable conditions for children born to Indiana women during 2005 – 2009 for each county in Indiana. Within this table, any count less than or equal to 5 is indicated with an asterisk (*).

Use of Indiana Birth Defects & Problems Registry Data

Annual data for births to Indiana mothers that occurred during the reporting period specified by the CDC (2005 – 2009) is contained in Table 6 and was submitted to the National Birth Defects Prevention Network (NBDPN) in August 2012; this data will be published in *Birth Defects Research Part A: Clinical and Molecular Teratology* in December 2012. Data from the IBDPR was not utilized by any researchers during this reporting period.

Proposals for the Prevention of Birth Defects and Problems in Indiana

Currently, the IBDPR contains a total of seven years' worth of information on birth defect rates within the state. This amount of information is not enough to allow IBDPR staff to accurately evaluate the presence of trends and/or clusters and, therefore, the need for specific prevention campaigns.

